

## **Washington State Genetics Task Force**

### **Minority Report**

**Philip L. Bereano**

In almost all the places where the Draft Report notes dissent, I am among those with a minority opinion. Therefore, I am combining my remarks in these observations, rather than trying to attach different comments to different sections.

#### **Overall**

New developments in the science of genetics and the technologies of genetic analysis have been accompanied by unprecedented hoopla and public attention. Indeed, the Human Genome Project is, far and away, the single largest and most expensive publicly supported biology activity of all time. Venture capitalist and scientists, abetted by sometimes uncritical media, have promoted an ideology of genetic determinism, claiming in a reductionist fashion that one's genes are the "blueprint" of one's future, despite the reality that the life of an organism is actually the result of complicated and ill-understood interactions between its genome and its environments. So, for example, BRCA-1 was routinely called "the breast cancer gene" although 95% of women having breast cancer do NOT have this allele. Thus, the populace has largely come to believe that variation from the genetic norm is evidence of "damaged goods."

The documentation in the peer-reviewed literature of over 200 cases of genetic discrimination a number of years ago, the passage of legislation on this topic by over 40 states in the last decade, two recent and well-publicized cases (Burlington Northern and Lawrence Labs), and an enormous literature—both scholarly and popular--testify to the reality of genetic privacy and discrimination as proper subjects of public policy. Yet, the Task Force essentially recommends no new initiatives to the Legislature, despite the fact that it has largely failed to address these concerns in its recent sessions. Since I believe that the State should take new action, I dissent from many of the Task Force's conclusions.

Despite its many hearings and the wealth of available literature, it is hard to avoid the conclusion that the Legislature established the Task Force in frustration at not being able to come to grips politically with the topic of genetics and discrimination. The composition of the group was dictated by the list of arbitrary categories (for example, there was no category of "disability rights activists", although that community has an extraordinary interest in the subject matter). The positions of the members were to a large extent evident at the first meeting and hardly changed over the course of our "deliberations." Thus, the outcome of the report is scarcely surprising either.

This is not to say that the individuals on the Task Force did not apply themselves with diligence and courtesy to the work before them; it is only an observation that the categorization of the Legislature's list is largely determinative of the resulting report.

Some members seemed to believe that, before we could consider any additional law or regulation, we had to find a concrete example of an instance of genetic discrimination that occurred within Washington (as if insurance companies or employers have differing social and economic interests in different states). In particular, the scientists on the Task Force wanted a "smoking gun."

But public policy isn't science; certainly some public policies are adopted to rectify past abuses, but others are designed to guide future conduct to avoid behaviors that are considered bad, whether or not these have already been manifested locally. "Teaching right conduct" is a well-recognized jurisprudential goal for statutes and regulations. If protecting genetic privacy is "right conduct" and if genetic discrimination violates norms of "right conduct," then it is permissible to pass a law or regulation even in the absence of documented abuses.

But of course, there is no reason to believe that genetic discrimination has NOT occurred here, especially since there are essentially no independent systems for reporting it (and protecting the victim) so as to provide monitoring of the situation. Since we don't look, we don't find; but that is not evidence that the problem doesn't locally exist.

The composition of the Task Force skewed it to consider health issues as the dominant policy arena (one in which Washington has, some argue, done something), and largely to ignore the fields of other kinds of insurance and employment. The Task Force's report provides scant support for omitting any recommendation to the Legislature for action in these arenas. This absence is alone sufficient to support my dissenting from the Report. But I have concerns about how the health issue itself was dealt with.

### **Genetic Discrimination / Privacy in the Health Field**

Subcommittee 3 (Research) relies on WAC 284.43.720 for the proposition that "predictive test results in the absence of a current diagnosis . . . cannot be requested or used by a [health] insurer in making decisions about insurability."

Although this may be the generally understood *interpretation* of the WAC, its language is not so clear.

Section (3) says that "genetic information shall not be treated as a health condition" if the person is asymptomatic. Section (1) says that insurers shall enroll people "regardless of . . . health conditions", and section (2) says that no

carrier may “deny, exclude, or otherwise limit coverage for an individual’s preexisting health conditions.”

If genetic information is NOT a “health condition”, then the WAC seems to mean that insurers CAN use that information to deny coverage, etc. If this is so, then the Subcommittee (and the Task Force as a whole) should be calling for legislation to limit the use of genetic information instead of assuming that it already is so limited in Washington.

The Subcommittee’s approach is based on a paradigm (“the altruistic researcher”) that is increasingly shown to be at variance with reality. Given the current ties between researchers—even academic researchers—and the corporate sector (*via* patent holdings, stock options, contracts, directorships, etc.), many researchers have a decided interest in the use of their research data that goes well beyond preparing a paper that will pass peer review. “All policymakers must be vigilant to the possibility of research data being manipulated by corporate bodies and of scientific colleagues being seduced by the material charms of industry. Trust is no defense against an aggressively deceptive corporate sector.” (The Lancet, April 2000)

The US Office of Research Integrity, a national monitoring agency, reported that 2001 had the highest number of misconduct cases in 25 years. (British Medical Journal 2002; 325:182; 27 July). Violations of patient confidentiality are on the front page of the *New York Times* (see, for example, “Free Prozac in Junk Mail Draws a Lawsuit,” July 6, 2002). Even prestigious local institutions such as the Fred Hutchinson Cancer Research Center have bent ethical boundaries (see, for example, “Judge: Hutch didn’t reveal study’s risk to patient”, Seattle Times, Aug. 9, 2002), and researchers have left the University of Washington for completely private work rather than submit even to minimal restrictions. And, just recently, the Administration has significantly weakened the proposed HIPPA data privacy rules by eliminating critical aspects of patient control (see New York Times and elsewhere).

Thus, I do not share my colleagues’ belief that the Legislature of Washington need not consider new legislation. Currently, residents of this state are at higher risk of having their genetic data misused than are residents elsewhere. And there is no justification for excluding research activities from the arenas where individuals ought to be able to determine what is done with information about them. No studies were provided to us indicating that respecting the genetic privacy of research subjects by requiring voluntary informed consent for the collection and use of their genetic information has inhibited research; indeed, I do not believe that there are any such studies at all.

None of us exists for the purpose of providing interesting data for the furtherance of someone else’s career or profit margin.

The Task Force, in my view, ought to be considering policy recommendations that will bolster peoples' confidence in the health care system, assuring that individuals have no hesitation about getting the diagnoses and treatments they may need. One-third of recent survey respondents feared that genetic testing might endanger their health insurance, and thus some refused to participate in research activities; these fears lead many to decline genetic counseling (Rothenberg and Terry, Science, 12 July 2002).

Instead, our recommendations acquiesce in a situation in which such confidence continues to erode. This is not only bad civil liberties policy; it is bad health policy as well.

## **Forensics**

I cannot subscribe to the position of Subcommittee 2 that tissue samples taken from individuals to create a database should not be destroyed after the DNA code is obtained. The subcommittee's view flies in the face of virtually all of the literature on the subject, even literature that is not very sensitive to civil liberties concerns (see, for example, Williamson and Duncan, "DNA Testing for All," Nature, 418, 585-6, 2002). These samples contain a great deal of biological information over and above anything that is germane to the DNA bank. Our recommendations, in my view, ought to be more consistent with the position of the Nation's Founders who were clearly skeptical of the use of power by forces of government, and advocated many practical ways to limit government as a result. Especially at this time, when the FBI and its parent agency the Justice Department are establishing sweeping new surveillance operations with hardly a nod to civil liberties, our Task Force ought to be less trusting. Colleagues who work with the CODIS system assure me that it is under no practical oversight. The government always claims that acknowledging civil liberties makes it less efficient; but ours was never designed to be the most efficient form of governance, only the most democratic. We should recommend that the tissue samples be destroyed after the purpose for taking them (getting the unique DNA code) has been satisfied.

Philip L. Bereano  
Professor, University of Washington  
Member of the National Board, American Civil Liberties Union